

Your genetic data—ethics

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In the entry #009, I wrote about how biology is slowly moving from the gathering of limited data about organisms to relying on mass genotyping. Even the biologists working entirely with squishy organisms are looking to the genetic databases for clues and cues. Here are a few more implications to that transition.

Implication four: Eugenics We can test for genetics not only among adults and children, but even fetuses. On one small survey, five out of 76 British ethics committee members (6.6%) “thought that screening for red hair and freckles (with a view to termination) was acceptable.”¹

Foetal gene screens to determine Down syndrome or other life-changing conditions are common, and 92% of fetuses that return positive for the test for Down Syndrome are aborted [Mansfield et al.].

Biology has an embarrassing past in eugenics. And we’re not just talking about the Nazis—the USA has a proud history of eugenics to go along with its proud history of hating immigrants (I mean recent immigrants, not the ones from fifty years ago, who are all swell). [The lead author of my last paper refers me to this article on eugenics², and having read it I too recommend the first 80%.]

If I may resort to a dictionary definition, the OED tells us that eugenics is the science “pertaining or adapted to the production of fine offspring, esp. in the human race.” In the past, that meant killing parents who turned out badly in life or had big noses, but hi-tech now allows us to go straight to getting rid of the offspring before anybody has put in too heavy an investment.

Anyway, I won’t go further with this, but to point out that what we’ll do with all this foetal genetic info is an open question—and a loaded one, since the only choices with a foetus are basically carry to term or abort. The consensus seems to be that aborting due to Down syndrome is OK and aborting due to red hair is not, but there’s a whole range in between. If you know your child has a near-certain chance of getting Alzheimer’s 80 years after birth, would you abort? [This Congressional testimony³ approximately asks this question.]

Implication five: the ethics of information aggregation This is also well-trodden turf, so I’ll be brief:

¹<http://adc.bmj.com/cgi/content/full/88/7/607>

²http://www.logosjournal.com/issue_6.1-2/jacobsen.htm

³<http://www.hhs.gov/asl/testify/t960917c.html>

- It is annoying and stupid that every time you show up at the doctor's office, the full-time paperwork person hands you a clipboard with eight papers, each of which asks your name, full address, and Social Security Number. By the seventh page, I sometimes write my address as "See previous pp" but they don't take kindly to that, because each page goes in a different filing cabinet.

You may recall Sebadoh's song on data and database management: "You can never be too pure/ or too connected." If all of your information is in one place, either on your magical RF-enabled telephone or somewhere in the amorphousness of the web, then that's less time everybody wastes filling in papers and then re-filling them in when the bureaucrat mis-keys everything. I have a FOAF whose immigration paperwork was delayed for a week or two because somebody spelled her name wrong on a form.

- Having all of your information in one place makes it easier for people to violate your privacy and security. As advertisers put it, it makes it easier to offer you goods and services better attuned to your lifestyle, which is the nice way of saying 'violate your privacy'. It means more things they can do to you on routine traffic stops.

The data consolidation=efficiency side is directly opposed to the data disaggregation=privacy side. There is no solution to this one, and both sides have their arguments. The current compromise is to consolidate more and put more locks on the data, but that doesn't work very well in practice, as one breach anywhere can ruin the privacy side of the system.

Back to genetics, when we have a few more snips of information about what all those genes do, your genetic info will certainly be in your medical records. This is a good thing because it means that those who need to will be able to diagnose you more quickly and efficiently; it is a bad thing because those who don't need to know may also find a way to find out personal information about you.

At the moment, you can rely on the anonymity of being a needle in a haystack, the way that some people who live at the top of high rise buildings are comfortable walking around naked and with the curtains open—who's gonna bother to look? But as the tools and filters and databases become more sophisticated, the haystack may provide less and less cover.

So we're going to have a haystack of data about you (and your foetus) right soon. Unfortunately, we don't quite yet know how to analyze, protect, or act on that haystack.

References

Caroline Mansfield, Suellen Hopfer, and Theresa M Marteau. Termination rates after prenatal diagnosis of Down syndrome, spina bifida, anencephaly, and Turner and Klinefelter syndromes: A systematic literature review. *Prenatal diagnosis*, 19(9): 808–812.